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Lay and health care professional understandings of self-management: A systematic review and narrative synthesis

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Lay and health care professional understandings of self-management: A systematic review and narrative synthesis

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Euan Sadler¹, Charles DA Wolfe^{1,2} and Christopher McKevitt^{1,2}

Abstract

Objectives: Self-management is widely promoted but evidence of effectiveness is limited. Policy encourages health care professionals to support people with long-term conditions to learn self-management skills, yet little is known about the extent to which both parties share a common understanding of self-management. Thus, we compared health care professional and lay understandings of self-management of long-term conditions.

Methods: Systematic review and narrative synthesis of qualitative studies identified from relevant electronic databases, hand-searching of references lists, citation tracking and recommendations by experts.

Results: In total, 55 studies were included and quality was assessed using a brief quality assessment tool. Three conceptual themes, each with two subthemes were generated: traditional and shifting models of the professional–patient relationship (self-management as a tool to promote compliance; different expectations of responsibility); quality of relationship between health care professional and lay person (self-management as a collaborative partnership; self-management as tailored support) and putting self-management into everyday practice (the lived experience of self-management; self-management as a social practice).

Conclusion: Self-management was conceptualised by health care professionals as incorporating both a biomedical model of compliance and individual responsibility. Lay people understood self-management in wider terms, reflecting biomedical, psychological and social domains and different expectations of responsibility. In different ways, both deviated from the dominant model of self-management underpinned by the concept of self-efficacy. Different understandings help to explain how self-management is practised and may help to account for limited evidence of effectiveness of self-management interventions.

Keywords

Self-management, long-term conditions, health care professionals, lay people, narrative synthesis

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Introduction

Self-management programmes are increasingly promoted as a policy response to the growing number of people living with long-term conditions (LTCs), and the associated economic implications of this.¹ The meaning of self-management, however, is contested, with no agreed upon definition of the term. A commonly used definition of self-management proposed by Barlow et al.² is ‘an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic condition’ (p. 366). Other definitions encompass social support from family, friends and wider community ties.^{3–5} Furthermore, self-management has been characterised as a key feature of contemporary health care systems, at the heart of which are

collaborative partnerships between patients and health care professionals (HCPs), aimed at promoting a culture of care fostering self-management.^{6–9}

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Self-management has also been proposed as a sub-category of the broader term 'self-care'.² Whereas the former relates to the ways in which individuals and their families manage the impact and effects of living with a chronic condition, the latter refers more generally to health promoting strategies used by lay people to maintain or optimise a state of health and well-being.³ However, the two terms have often been used synonymously in the policy^{10,11} and health services research literature.^{3,12} This slippage in terminology makes it difficult to understand what is actually meant by self-management of LTCs.

Self-management interventions may include lay or professionally led and group-or individual-based approaches,^{13,14} but commonly they target people with a range of chronic conditions as part of a group programme modelled on the Chronic Disease Self-Management Programme (CDSMP) developed by Lorig and colleagues^{15,16} in the United States. This largely biomedical model of self-management aims to empower people with LTCs to learn new skills and knowledge (e.g. problem solving, shared decision making, utilisation of resources) in partnership with HCPs. Such an approach has been adapted in the United Kingdom as the Expert Patient Programme (EPP)¹⁷ and in Australia as the 'Sharing Health Care' programme.¹⁸ These interventions are based on Bandura's¹⁹ social cognitive theory of behaviour, in which individuals learn self-efficacy enhancing skills to improve their ability to manage the everyday challenges of living with a chronic condition. Drawing on self-regulation theory²⁰ (also rooted in social cognitive theory), self-regulation models of chronic disease self-management proposed by Clark and colleagues²¹⁻²³ have further informed the self-efficacy literature. Such scholars propose that individuals' perception of ability to change or modify behaviours occurs through self-regulatory mechanisms, for example, in terms of their judgement of the benefits and importance of a particular goal, and beliefs about health and illness, which is partly influenced by a person's social environment. Thus, self-regulation in turn influences self-efficacy, decision making processes and ongoing engagement in self-management behaviours.

Programmes based on psychological models of self-management have been criticised for their individualistic, biomedical and prescriptive focus on disease management, that fall short of addressing lay understandings of self-management and the social context shaping self-management practices.^{18,24-26} Such approaches have not incorporated phenomenological perspectives that draw our attention to the lived experience of self-management.²⁷ Nor do they integrate the extensive body of sociological research on 'illness narratives', depicting the varied ways in which lay people make sense, cope and manage a chronic condition in their everyday lives.²⁴ Illness narratives are embedded in social practices and social support from family and other social networks.^{5,24} In line with social support theory, however, this process may involve both positive and negative

influences,^{28,29} which in turn may impact on self-management practices.

Current evidence for the benefits of self-management programmes remains equivocal³⁰⁻³² and patient engagement is limited.³⁰ For example, a Cochrane Review of 17 randomised controlled trials of lay-led self-management programmes for individuals with a range of LTCs (including, diabetes, arthritis and chronic pain) found only short-term improvements in some patient outcomes, including self-rated health and self-efficacy, but little or no effect on other outcomes, such as psychological health, quality of life and use of health services.³⁰ Possible explanations for these mixed results relate to methodological issues, such as the heterogeneous nature and delivery of trials and outcome measures used,² as well as the characteristics of participants taking part, mostly well-educated women, with limited engagement among men and those from minority ethnic groups.^{30,33} Other explanations proposed by Osborne et al.³⁴ point to the lack of attention given to addressing social and structural factors shaping self-management practices, including inequitable access to services, social disadvantage and social isolation, and the lack of integration of self-management programmes in routine health care.

State-driven interventions such as the EPP¹⁰ designed to support lay people to learn self-management skills are based on an implicit shift in responsibility from professional to lay person in terms of managing the burden of disease and psychosocial impact of living with a chronic condition.^{7,35} It is often assumed that individuals living with one or more LTCs have a prior interest in managing their health through such an approach, arguably attracting those who might 'buy into' the notion of self-management and who are already good 'self-managers'.³⁶ However, the lack of patient engagement in such initiatives suggests that many lay people may not share the policy's concern to manage their health in this way.

Increasingly, HCPs are encouraged to support individuals with LTCs to learn self-management skills.¹¹ This implies a shared understanding of the concepts of self-management; something about which little is known. Thus, the aim of the current review is to conduct a systematic review and narrative synthesis of qualitative studies to compare lay and HCP understandings of self-management of LTCs.

Methods

We used a number of methods to search for relevant studies, which is recommended when looking for qualitative evidence from varied sources.³⁷ This included searching electronic databases, hand-searching reference lists, citation tracking and recommendations by experts in the field. We included qualitative studies examining lay and/or HCP understandings of self-management published in peer-reviewed English language journals. We excluded studies that used only questionnaire designs and quantitative analyses and intervention studies as our focus was not to look at

why self-management interventions worked or not. We also excluded conference papers and solely theoretical articles.

First, we searched SCOPUS, Web of Science, CINAHL and PsycINFO electronic databases from inception until May 2013. The search strategy used MeSH and free text terminology combining the terms: ('Self-Management' OR 'Self-Care' OR 'Self-Help') AND 'Qualitative' AND ('Long Term Condition*' OR 'Chronic Disease*' OR 'Chronic Illness*' OR 'Diabetes' OR 'Arthritis' OR 'Asthma' OR 'Cancer' OR 'Chronic Obstructive Pulmonary Disease' OR 'Stroke' OR 'Multiple Sclerosis' OR 'Traumatic Brain Injury' OR 'Acquired Brain Injury') AND ('Health Care Professional*' OR 'General Practitioner*' OR 'Nurse*' OR 'Allied Health Professional*' OR 'Patient*' OR 'Carer*' OR 'Caregiver*'). Titles of all articles were read, non-relevant studies excluded (for example, intervention studies) and duplicates removed. Remaining abstracts were then reviewed and potentially relevant articles retrieved and read in full. Studies which did not meet the inclusion criteria after full reading were discarded (for example, those not directly focusing on self-management or more narrowly focusing on self-management of specific disease symptoms only, such as control of blood glucose levels or breathlessness).

Second, we hand-searched reference lists of included articles for further studies that met the inclusion criteria. Again, potentially relevant articles were retrieved and read in full to assess whether they met the inclusion criteria. Third, we used citation tracking in Google Scholar of all relevant studies retrieved from the above electronic and hand searches to look for further articles up until March 2014. Finally, recommendations were made of relevant articles by experts working in the fields of health services research and primary care.

Data extraction and method of synthesis

We used a narrative synthesis approach to provide a narrative, textual account of similarities and differences in HCP and lay understandings of self-management of chronic conditions. We drew on the Economic Social Research Council's (ESRC) research programme methods guidance³⁸ on using different methods during synthesis which aims to improve the quality and transparency of the review process. In line with their guidance, we adopted a flexible, iterative approach to conducting the stages of the synthesis, and we used tabulation and thematic analysis to compare similarities and differences among HCPs and lay people. E.S. constructed tables using relevant sub-headings (i.e. author, country, sample, method, theoretical approaches used and main themes) (see Table 1). Once tabulation was complete, E.S. and C.M. undertook a thematic analysis of key findings from included studies using the 'one sheet of paper method'.³⁹ This involved first individually coding the findings of included studies from tables into initial themes and then using the principles of the constant comparative method⁴⁰ to look for similarities and differences between themes, grouping these into broader

conceptual themes visually displayed on one sheet of paper. E.S. and C.M. then discussed relationships between themes and also considered the theoretical basis for the approaches used, which led to a joint consensus on the main emerging conceptual themes and subthemes of the synthesis.

Robustness of the synthesis

Two authors (E.S. and C.M.) first independently considered the quality of included articles using the five-point checklist by Dixon-Woods et al.⁴¹ (see Box 1). This checklist is a brief way of evaluating the quality of studies in relation to their aims, methods, results and conclusions and involved giving each study a score out of 5 based on whether they were judged to meet five specific criteria (Box 1). For example, a score of 5 meant that all five criteria were met in one study. E.S. and C.M. then discussed together the individual quality scores given. Overall, there were no disagreements between the two authors in terms of quality scores ascribed to individual studies.

Box 1. Criteria used to assess quality in included studies.⁴¹

Are the aims and objectives of the research clearly stated?
Is the research design clearly specified and appropriate for the aims and objectives of the research?
Do the researchers provide a clear account of the process by which their findings were reproduced?
Do the researchers display enough data to support their interpretations and conclusions?
Is the method of analysis appropriate and adequately explicated?

As quality appraisal methods for assessing the quality of qualitative studies is a contested area of debate,⁴² we did not exclude articles based on lower ascribed quality scores, but we decided to use this information to appraise the robustness of the findings in the results and discussion. To reduce potential bias affecting the robustness of the synthesis and findings, we further undertook a sensitivity analysis reanalysing the results after removing studies with lower quality scores (i.e. those with a score of 3 or less out of 5). As the checklist focuses on appraisal of the technical quality of the research design, rather than theoretical approaches used,⁴³ we aimed to consider in the discussion how the theoretical approaches used could have impacted on the quality of results.

Results

In all, 760 articles were identified through electronic searching; following the removal of 219 duplicates, 541 articles were left. Titles and abstracts of these articles were read, and 476 articles were excluded as they did not meet the inclusion criteria (e.g. intervention study). Full-text articles were obtained for 65 studies that appeared to meet the inclusion criteria. Following full reading of these articles, a further 34

Table 1. Included studies in the synthesis.

Author	Country	Sample	Method	Theoretical approach	Theme			Collaborative partnership	Tailored support	Lived experience	Social practice
					Compliance	Responsibility					
Hunt and Arar ⁴⁴	USA	51 Mexican-American patients with type 2 diabetes; 35 HCPs recruited from public clinics	Interviews	Medical anthropological (explanatory models)	X	X				X	
Carbone et al. ⁴⁵	USA	37 Latino patients with type 2 diabetes; 15 HCPs recruited from a community health centre	Focus groups	–	X				X		
Crowe et al. ⁴⁶	New Zealand	64 patients with chronic low back pain; 22 HCPs recruited through advertisement, newsletter and physiotherapy clinics	Interviews	–	X	X				X	
Blakeman et al. ⁴⁷	UK	12 patients with range of LTCs (including diabetes, IHD, stroke and asthma); 17 HCPs recruited from GP practices	Interviews and observations of clinical consultations	–		X				X	
Kirby et al. ⁴⁸	Australia	33 patients with range of LTCs (e.g. chronic respiratory problems or heart failure); 18 clinicians recruited from hospital and primary care	Interviews	Psychological (social cognitive theory)	X	X					
Pooley et al. ⁴⁹	UK	47 patients with type 2 diabetes; 38 HCPs recruited from GP practices	Interviews	–			X		X		
Yen et al. ⁵⁰	Australia	88 primary care HCPs working with patients with a range of LTCs (COPD, diabetes and CHF) recruited from primary care settings	Focus groups	–	X	X					
Lake and Staiger ⁵¹	Australia	31 HCPs (e.g. GPs, nurses, psychologists) working with patients with range of LTCs recruited from acute, primary and community health care settings	Group and individual interviews	–		X	X		X		X
Blakeman et al. ⁵²	UK	16 GPs working with patients with a range of LTCs recruited from two primary care trusts	Interviews	Social science (Howie's theoretical model applied to GP consultations)		X					
Macdonald et al. ⁵³	UK	25 nurses working with individuals with range of LTCs recruited from chronic disease clinics	Interviews	Psychosocial ('trajectory model' and 'personal construct' theories)			X		X		X

Table 1. (Continued)

Author	Country	Sample	Method	Theoretical approach	Theme				
					Compliance	Responsibility	Collaborative partnership	Tailored support	Lived experience
Phillips et al. ⁵⁴	Australia	14 clinicians working with patients with range of LTCs recruited from hospital and community urban settings	Telephone interviews and survey	–	X			X	
Guidetti et al. ⁵⁵	Sweden	12 occupational therapists working with stroke and SCI patients recruited from a rehabilitation setting	Interviews	Phenomenological			X	X	
Ofedal et al. ⁵⁶	Norway	19 people with type 2 diabetes recruited from a hospital, educational programme, local diabetes association and GP practices	Focus groups	–			X	X	
Thorne and Paterson ⁵⁷	Canada	22 adults with type 1 diabetes identified as experts in self-care nominated by clinicians	Multiple interviews. Grounded theory approach	–			X	X	
Guidetti et al. ⁵⁸	Sweden	5 stroke patients and 6 patients with SCI recruited from a rehabilitation setting	Interviews	Phenomenological					X
Guidetti et al. ⁵⁹	Sweden	5 stroke patients and 6 patients with SCI recruited from a rehabilitation setting	Interviews	Phenomenological			X		X
Opal Cox et al. ⁶⁰	USA	39 older stroke survivors (aged 62 years and over) recruited from a rehabilitation hospital	Interviews	–	X	X	X		X
Pound et al. ⁶¹	UK	40 stroke survivors living in a working-class area of London identified from a stroke register of hospital admissions	Interviews	Sociological (illness narratives)					X
Auduly et al. ⁶²	Sweden	26 people with range of LTCs (diabetes, MS, rheumatic disease and IBD) recruited from an outpatient clinic	Narrative interviews	Psychological ('responsibility attribution')	X	X			X
Kralik et al. ⁶³	Australia	9 middle-aged older-aged adults with chronic arthritis recruited from an advertisement in a community newsletter	Focus group, written autobiographical accounts and telephone interviews	Psychosocial (experience of transitions)	X				X

(Continued)

Table 1. (Continued)

Author	Country	Sample	Method	Theoretical approach	Theme					
					Compliance	Responsibility	Collaborative partnership	Tailored support	Lived experience	Social practice
Atkin et al. ⁶⁴	UK	23 individuals with encephalitis recruited from a national voluntary organisation	Interviews	Sociological (illness narratives)					X	X
Kielman et al. ⁶⁵	UK	31 patients with chronic respiratory conditions recruited through primary care organisations	Focus groups, diaries and telephone interviews	Social science ('self-care', 'lay knowledge' and 'patient-provider interactions')		X	X			
Koch et al. ⁶⁶	Australia	24 older people (aged 60 years and over) with asthma recruited using range of methods (including newspapers and contacting community health workers)	Interviews, questionnaires and participatory action research groups	–	X	X	X		X	
Collins et al. ⁶⁷	Ireland	17 patients with type 1 and 2 diabetes recruited from GP practices and diabetic clinics	Interviews	–	X	X				
Townsend et al. ⁶⁸	UK	23 people with multiple LTCs taking part in a community health survey	Repeat narrative interviews	Sociological (illness narratives)					X	
Schulman-Green et al. ⁶⁹	USA	15 women with advanced breast cancer recruited from a hospital cancer centre	Interviews	–			X		X	X
Cooper et al. ⁷⁰	UK	24 patients with IBD aged between 30 and 40 years recruited from outpatient clinics	Interviews	–			X		X	
Clark et al. ⁷¹	USA	23 older individuals (aged 65 years and over) from white and black ethnic groups with range of LTCs from low-income groups and 12 with private health insurance recruited from primary care settings	Interviews	Psychological (identity theory)	X	X			X	
Chen et al. ⁷²	Taiwan	18 patients with COPD recruited from a hospital ward, outpatient and rehabilitation settings	Interviews	–	X				X	
Hjelm et al. ⁷³	Sweden	15 Swedish-born and 13 Yugoslavian-born women with diabetes recruited from primary health care centres	Focus groups	Medical anthropological (lay models of illness causation and health-care seeking behaviours)	X	X				

Table 1. (Continued)

Author	Country	Sample	Method	Theoretical approach	Theme				
					Compliance	Responsibility	Collaborative partnership	Tailored support	Lived experience
Ploughman et al. ⁷⁴	Canada	18 people aged 55 years and over with MS recruited from MS clinics and outpatient rehabilitation setting	Narrative interviews	Life-course perspective	X	X	X	X	X
Dixon et al. ⁷⁵	USA	27 people with at least one LTC recruited from non-faculty university staff	Interviews	–	X	X		X	X
Furler et al. ⁷⁶	Australia	Ethnically diverse sample of 52 people with type 2 diabetes recruited from community health service and support groups	Focus groups	–			X		
Gunn et al. ⁷⁷	United Kingdom	45 people with type 1 or type 2 diabetes living in urban and rural areas admitted to hospital and identified by specialist practitioners	Interviews	–					X
Gallant et al. ⁷⁸	USA	84 people aged 65 years and over from white and African American ethnic backgrounds with range of LTCs (arthritis, diabetes and heart disease) recruited from a range of community organisations	Focus groups	Psychosocial (social cognitive theory and social support theories)					X
McLaughlin and Zeeberg ⁷⁹	Denmark and USA	51 community-dwelling Danish and 35 American adults with MS	Ethnographic approach: participant observations, interviews and self-reported self-care behaviour questionnaire	–				X	
Stamm et al. ⁸⁰	Austria	10 people with RA recruited from rheumatology outpatients clinic	Repeat narrative interviews	Sociological (biographical approach)				X	
Lindsay ⁸¹	UK	53 people with multiple LTCs recruited from CHD registries, as part of a larger RCT study	Focus groups	Sociological ('chronic illness trajectories')				X	
Cicutto et al. ⁸²	Canada	42 individuals with COPD recruited through range of methods (posters in physician and rehabilitation clinics, newsletter and newspaper advertisements)	Focus groups	–			X	X	X

(Continued)

Table 1. (Continued)

Author	Country	Sample	Method	Theoretical approach	Theme					
					Compliance	Responsibility	Collaborative partnership	Tailored support	Lived experience	Social practice
Loignon et al. ⁸³	Canada	24 people with asthma from low- and middle-income backgrounds recruited from a general hospital and snowball sampling techniques	Interviews	Sociological (illness narratives)	X	X				
Auduly et al. ⁸⁴	Sweden	26 people with range of LTCs (RA, diabetes, IBS, MS, IHD, kidney failure)	Narrative interviews, grounded theory approach	–				X	X	X
Goodacre ⁸⁵	UK	12 women with chronic arthritis recruited from local arthritis self-help groups	Repeat interviews, diaries and focus groups	Sociological (illness narratives)				X		
Kidd et al. ⁸⁶	UK	11 patients with colorectal cancer recruited from a cancer centre	Repeat interviews	Psychological (self-regulation theory)				X	X	X
Chiu-Chu et al. ⁸⁷	Taiwan	41 patients with type 2 diabetes recruited from hospital clinics	Focus groups	Psychological (self-regulation theory)				X	X	
Corbin and Strauss ⁸⁸	USA	60 people with a range of LTCs (mainly cardiac disease, cancer, stroke, SCI) and their carers	Interviews	Sociological ('illness trajectories')				X	X	
Kenning et al. ⁸⁹	UK	20 patients with multiple LTCs (CHD, diabetes, osteoarthritis, COPD and depression) identified from disease registries and HCPs recruited from GP practices, as part of a larger cohort study	Interviews	–	X					
Hinder and Greenhalgh ⁹⁰	UK	Ethnically diverse sample of 30 people with type 1 and type 2 diabetes recruited from patient groups, primary and secondary health care clinics, community contacts and ethnic minority groups	Ethnographic approach, including home observations and interviews	Sociological ('structuration theory')	X			X		X
Morris et al. ⁹¹	UK	21 individuals with multiple LTCs recruited from two GP practices (part of a qualitative study within an RCT)	Interviews	–			X	X	X	

Table 1. (Continued)

Author	Country	Sample	Method	Theoretical approach	Theme			Lived experience	Social practice
					Compliance	Responsibility	Collaborative partnership	Tailored support	
Greenhalgh et al. ⁹²	UK	82 individuals with type 1 and type 2 diabetes from minority ethnic groups taking part in an RCT study on storytelling	Ethnographic approach: observations and field notes of group discussions	Biomedical and sociological (illness narratives)				X	X
Ong et al. ⁹³	UK	22 individuals aged 50 years and over with chronic knee pain, drawn from a cohort study	Repeat interviews and diaries	Sociological (illness narratives)				X	
Clarke and Bennett ⁹⁴	Canada	35 older people (aged 73–91 years) with multiple LTCs recruited through newspaper advertisements and database of participants taking part in a previous study	Multiple interviews	Sociological (illness narratives)				X	
Pickard and Rogers ⁹⁵	UK	Patients with multiple LTCs (including diabetes, kidney disease and hypertension) and their carers recruited from patient records in GP practices	Multiple interviews, focuses on one case study	Phenomenological and sociological (illness narratives)		X	X	X	X
Auduly et al. ⁹⁶	Sweden	21 people with range of LTCs recruited from an outpatient hospital clinic	Multiple interviews. Grounded theory approach	–				X	X
Samuel-Hodge et al. ⁹⁷	USA	35 African American adults with type 2 diabetes and 32 of their family members recruited through flyers by 'community recruiters'	Focus groups	–					X
Essue et al. ⁹⁸	Australia	Ethnically diverse sample of 14 carers of patients with a range of LTCs (CHF, COPD, diabetes), who took part in wider study	Secondary qualitative analysis of interviews	–					X

HCP: health care professional; GP: general practitioner; LTC: long-term condition; IHD: ischaemic heart disease; COPD: coronary obstructive pulmonary disease; CHD: congestive heart disease; CHF: congestive heart failure; SCI: spinal cord injury; RA: rheumatoid arthritis; MS: multiple sclerosis; IBD: inflammatory bowel disease; IBS: irritable bowel syndrome; RCT: randomised controlled trial.

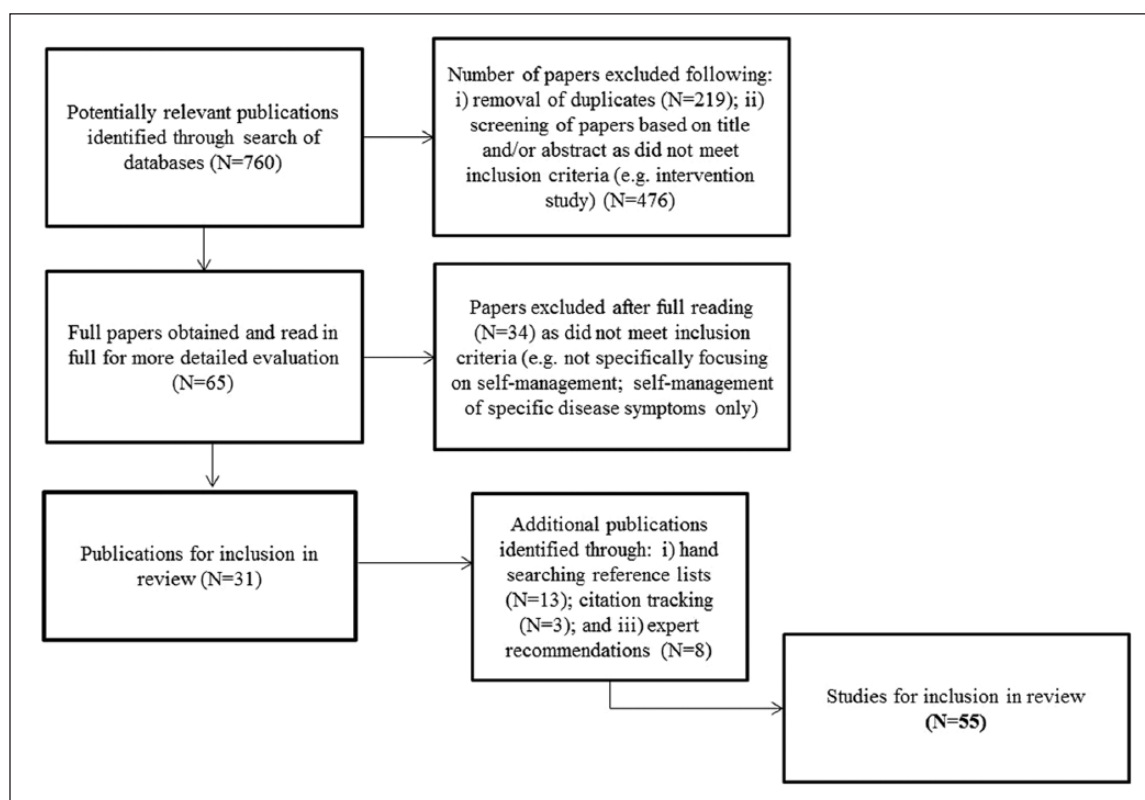


Figure 1. Flow of studies through the stages of the review.

studies were discarded for not meeting the inclusion criteria, which left 31 studies. Through hand-searching reference lists of these studies, 13 additional articles were then identified. Finally, a further three articles were obtained through citation tracking and eight through recommendations by experts in the field. In total, 55 studies were included in the review (Figure 1).

Overview of included studies

Table 1 summarises the main characteristics of the articles included in the review. Studies were from 11 countries, most from the United Kingdom (19); then the United States (9); Australia (8); Sweden (7); Canada (5); Taiwan (2) and one each from New Zealand; Norway; Ireland; Austria; as well as one cross-cultural study (United States/Denmark). Overall, authors tended to use the terms self-management or self-care synonymously. The majority of studies (N=41) investigated understandings of self-management or self-care among individuals with one (N=34) or multiple conditions (N=7) (three studies also included carers); one focused on carers' perspectives only; six on HCPs (including general practitioners (GPs), nurses, psychologists and allied health professionals) and seven both lay people and HCPs.

Over one-third of studies (N=22) investigated self-management or self-care among people with a range of LTCs (such as diabetes, heart disease, arthritis, asthma, chronic

obstructive pulmonary disease (COPD), stroke); 13 focused on individuals with diabetes; 7 stroke/other neurological conditions; 2 asthma; 3 COPD/other chronic respiratory conditions; 3 arthritis (osteoarthritis or rheumatoid arthritis); 2 chronic pain; 2 cancer and 1 inflammatory bowel disease (IBD).

Robustness of findings

Overall, the quality of included articles was high, with a mean score of 4.7 out of 5. Only three of the 55 articles were rated by both authors as lower quality (scoring 3 out of 5). A sensitivity analysis on the main themes emerging from the synthesis suggested that the findings were robust after removing these three lower quality score studies. In terms of theoretical approaches used, under one-half of included studies (N=26) did not explicitly use a theoretical framework. The other 29 studies drew on theoretical approaches to investigate lay and, to a lesser extent, HCP understandings of self-management or self-care: 11 used sociological theory (e.g. illness narratives), 5 psychological approaches (e.g. social cognitive theory, self-regulation theory), 3 phenomenological, 2 medical anthropological, 2 other social science approaches, 3 psychosocial and 1 each of the following: a combination of biomedical and sociological; phenomenological and sociological and life-course approaches.

The synthesis

We generated three main conceptual themes, each with two subthemes, which we now discuss.

Traditional and shifting models of the professional–patient relationship

The studies suggest that HCP and lay understandings of self-management encompass traditional or paternalistic models of the professional–patient relationship based on compliance. They also entailed shifting models of this relationship based on different expectations of responsibility.

Self-management as a tool to promote compliance. Self-management was commonly interpreted among HCPs as a tool to promote compliance with expert advice and medical regimes, to encourage people with LTCs to monitor and control symptoms of disease, engage in healthy lifestyle behaviours^{44–46,48,50,54,89} and learn psychological skills, such as problem solving and goal setting.^{53,55} It was assumed by some medical practitioners that lay people lack the ability to self-manage, and require information to educate, motivate and build confidence in their ability to self-manage and thus comply with recommended strategies. For example, a hospital doctor in one study working with patients with a range of chronic conditions noted,

If you educate patients about their condition, about their medications, they have a great familiarity and that familiarity breeds confidence, that confidence means that they're comfortable with their condition. It means they'll self-manage.⁵⁰ (p. 14)

Poor compliance was attributed by HCPs to negative psychological characteristics of patients. This was often assumed to be related to poor motivation and a lack of willingness to engage in self-management practices in the longer term:^{44,45,50,54,89}

... unless [patients] are motivated and engaged they will not get anywhere. This is critical to the success of any intervention.⁵⁴ (p. D)

Compliance is a big issue and they have to get their head around that idea that it'll be OK if they do what they're supposed to do, but they're not used to doing that.⁵⁰ (p. 13)

Two studies also found that medical practitioners considered compliance with professionally ascribed self-management practices required the 'right' cultural context.^{44,45} For example, a hospital doctor in one study of Mexican–Americans with type 2 diabetes commented,

I'd say more than 90 percent of them are noncompliant. I understand because of the culture, the diet is very difficult for them to adjust to.⁴⁴ (p. 355)

Lay people similarly sometimes understood self-management as compliance with professionally recommended behaviours in terms of following medication, exercise or diet regimes.^{60,66,71–75,83} Expectations for a professionally led compliance approach to self-management among lay people was influenced by individual factors, such as lower perceived levels of activation⁷⁵ (i.e. skills, knowledge and confidence) and emotional difficulties,⁷⁶ but also social factors, such as low education⁷¹ and cultural beliefs that placed trust in professional expertise and knowledge.^{66,72,73,83} For example, one participant with COPD in a study conducted in Taiwan said,

Now, when I am told to exercise, I listen. They are doctors and nurses who have experience. We know nothing. You should just follow the orders.⁷² (p. 599)

In several studies people with a range of LTCs, such as osteoarthritis, cancer, asthma and COPD, spoke about their attempts to comply with professional advice regarding self-management practices, but experienced difficulties doing so due to a number of factors. Individual factors included emotional difficulties,^{69,76,89,90} poor health^{83,89} and cognitive impairment.⁹⁰ Organisational and structural factors limiting compliance included a lack of information,^{69,95} poorly coordinated or fragmented community services,⁴⁸ limited consultation time with HCPs⁴⁹ and poor socio-economic circumstances.^{44,45,83,90}

Different expectations of responsibility. Lay and HCP understandings of self-management also encompassed shifting models of the professional–patient relationship based on different expectations of responsibility. HCPs commonly expected patients to take increased personal responsibility to manage their own health.^{44,48,50,51} There was some evidence that they made moral assessments of people's willingness and ability to take responsibility, with a lack of willingness regarded as problematic for effective self-management.^{44,48,89} In one study, such a viewpoint was particularly evident among hospital clinicians and GPs:

They don't want to take responsibility. A lot of them think someone else will look after their health. [they] expect someone else to fix it.⁴⁸ (p. 225)

Some GPs regarded self-management as conflicting with traditional health care practices and professional values of responsibility to patients.⁵² Self-management was also found in one study to be a marginalised topic of discussion in routine clinical encounters between GPs/nurses and patients, shaped by mutual expectations to maintain traditional professional–patient boundaries in such relationships.⁴⁷

Lay people's understandings of self-management suggested variations in expectations of responsibility. Some people, but not all, welcomed greater personal responsibility

to manage their conditions.^{46,60,62,63,65–67,71,73,75,83} Some interpreted self-management as compliance with professional advice,^{60,65} while others preferred to combine professional advice with personal experience^{46,62,74} or made their own decisions regarding treatments, such as the use of alternative medicines.^{73,83}

Lay people who interpreted self-management in terms of expectations of increased personal responsibility reported wanting to take an active role in decision making and problem solving,^{62,67,71} adopt health promoting strategies,⁷¹ use a higher number of coping strategies,⁷⁵ integrate self-management practices into daily routines⁶² and learn through trial and error.^{63,74} For example, a participant with arthritis in one study said,

If you want to do something then work out how to do it and what you need to do it ... you can usually find a way to get things done.⁶³ (p. 263)

Lay understandings of self-management sometimes entailed expectations that responsibility in learning self-management skills would be shared with HCPs.^{60,66,74,95} For example, one stroke survivor in another study noted,

It's their responsibility to use their expertise with respect for us individuals, and our responsibility to meet them halfway.⁶⁰ (p. 84)

In contrast, some participants in a number of studies refused the idea of self-management, preferring instead to follow orders from doctors and other HCPs.^{62,65–67,71,74,75,89} A dependence on HCPs to provide support in learning self-management skills was influenced by beliefs that one had little control over the course of illness or that illness was attributed to external causes (e.g. supernatural causes),⁷³ reduced knowledge, skills and confidence,⁷⁵ low education⁷¹ and lack of social support.⁷⁴ This sometimes led to feeling abandoned by HCPs when services had come to an end,⁶⁵ as one participant with asthma in a further study said,

I said 'Well why are you only seeing me every month or two?' 'Oh well, you always seem to be able to manage'. And so well, I can, but should I be, should I be just doing it all on my own, do you know what I mean? I don't know, the more independent and able to manage you are the less keen they are to see you sometimes.⁶⁵ (p. 58)

Quality of relationship between HCP and lay person

Lay people interpreted self-management in terms of the quality of relationship with a HCP, which was much less often reported among professionals. The quality of relationship included two aspects: self-management as a collaborative partnership and tailored support to meet the needs and situation of the individual.

Self-management as a collaborative partnership. In 14 studies, individuals with a range of LTCs, and those living with multiple chronic conditions, regarded self-management as a practice that was achieved through a collaborative partnership with a HCP.^{49,56,57,59,60,65,66,69,70,74,76,82,91,95} They identified the quality of this partnership as an important contextual factor fostering self-management practice. This included an expectation of being jointly involved in decision making,^{56,66} building a relationship based on mutual respect^{60,74} and trust,^{60,65} and that HCPs should endeavour to understand the 'whole' needs of the person to better integrate self-management practices into their everyday lives.^{82,95} Lay people further placed importance on their views, preferences, knowledge and expertise being part of the process of learning self-management skills.^{49,65,66,74}

Other aspects of a collaborative partnership identified by lay people as part of self-management pointed to HCP relationships that were encouraging,^{57,60,70} empathetic,⁵⁶ flexible and accessible,^{57,65} based on good communication^{57,59,69,91} and involving the provision of emotional support, reassurance^{76,82} and choice⁷⁴. For example, in one study, a participant with multiple sclerosis (MS) commented,

We understood each other. He listened to what I had to say and paid attention to what I said. He told me about everything that was going on, but he left it to me to decide if I wanted to take part or not.⁷⁴ (p. 13)

HCPs less commonly alluded to a collaborative partnership as part of self-management.^{51,53,55} In one study, this was interpreted among HCPs across acute, primary and community care settings as working together as part of an equal alliance.⁵¹ In two other studies, nurses⁵³ and rehabilitation therapists⁵⁵ regarded nurturing such a relationship as integral to supporting lay self-management practices. This entailed developing a trusting, enabling and guiding relationship;⁵⁵ listening to individual needs and concerns;^{53,55} involving carers in providing appropriate support⁵³ and recognising patients' own expertise.⁵⁵ For example, one occupational therapist working in a rehabilitation setting with stroke and spinal cord injury (SCI) patients said,

Maybe I am the person who has supported them in this process – but it is absolutely not me who is the expert any more.⁵⁵ (p. 265)

Self-management as tailored support. A proportion of participants in several studies understood self-management as the provision of tailored support to meet individual needs and situations, which was seen as a further marker of the quality of the HCP–patient relationship.^{45,49,56,57,91,95} This reflected expectations for professional guidance and support in terms of diet,⁴⁹ exercise,⁴⁵ practical⁵⁶ or emotional support⁴⁵ and information.^{56,91,95} Furthermore, lay people expected HCPs to provide information that would meet changing learning

needs over time⁵⁷ and support self-management regimes for those with multiple conditions.⁹¹ Provision of consistent information provided by a range of HCPs was identified as a valued component of self-management, but this was perceived as not always forthcoming, as a participant with diabetes in one study said,

It is obvious that the level of knowledge varies, and they tell me different things. It is a big problem.⁵⁶ (p. 1505)

HCP understandings of self-management similarly entailed tailored responses to meet individual needs of people with different chronic conditions.^{49,51,54,55} However, professionals spoke about organisational challenges limiting the provision of tailored support for those with LTCs, including fragmentation of community services⁵⁰ and lack of professional training.⁵¹ Occasionally, this reflected the recognition among professionals that learning self-management skills should be adapted to individual ability, preferences, prior roles and activities.⁵⁵ In one study, HCP understandings of self-management encompassed a flexible and eclectic approach and access to a diversity of self-management support initiatives to meet the varied and changing needs of people with a range of LTCs.⁵¹ One clinician defined self-management as

... an individual approach, looking at the stages of change and allowing an individual program. Having different strategies and different interventions is important.⁵¹ (p. 64)

Putting self-management into everyday practice

Lay understandings of self-management entailed variations in how individuals with chronic conditions attempted to put self-management into everyday practice. This process involved learnt biomedical and psychological strategies, but also aspects largely unacknowledged by professionals, including different preferences for self-management, the construction of meaning-making frameworks, social strategies and practices. Two interrelated emerging subthemes were the lived experience of self-management and self-management as a social practice.

The lived experience of self-management. In a number of studies, lay people understood self-management in terms of biomedical and psychological strategies to modify behaviours. Biomedical strategies comprised monitoring and managing bodily symptoms^{44,46,79,80,85,92} and levels of activity^{61,63,72}, and engagement in diet,^{44,45,60,62,73,86,87,92} exercise^{45,46,60,61,62,72,92} and medication regimes.^{44,46,71,83,86,91,92} Psychological strategies involved problem solving,^{46,70,74} action planning,⁹⁶ evaluation and reflection^{44,79,87,93} in relation to self-management of daily tasks. Self-management was also understood to involve managing the emotional impact of living with a chronic condition, for example, in dealing with fear and uncertainty of the future.^{72,76,86,90}

Lay understandings of self-management involved different preferences for engagement in self-management practices.^{68,69,70,72,81,84,86,89,90} Variations were shaped by a number of factors, including individual ability,⁹⁰ changes in the course of illness,⁶⁹ cultural beliefs in health and illness,^{73,84} perceived level of disruption to one's life and biography^{89,91} and competing social roles.^{63,70,84} In terms of the latter, this sometimes led to a tension in perceived priorities, in relation to balancing self-management activities with other valued social roles, which had implications for health, as a woman with rheumatoid arthritis with other health problems in one study said,

I tend to overdo it sometimes and I suffer badly for it as well ... like, say, my daughter's moving house there, giving her a hand recently, we were doing cleaning of the place and I suffered for about three days after it ... I was in absolute agony, agony ... the doctor gave me painkillers ... But at the end of the day, it's your daughter and you do it and that's it, it's your family ... The illness comes secondary to your family ...⁶⁸ (p. 191)

The lived experience of self-management further involved the construction of different meaning frameworks as part of illness narratives,²⁴ which lay people drew upon to make sense of, and cope with, the challenges of living with a chronic condition.^{63,64,66,70,74,75,79,80,82,86,92} These included the following: maintaining a positive attitude,^{64,74,80} finding a sense of purpose,^{82,92} restoring order in the face of uncertainty,^{58,63,79} managing identity^{63,64,86} and biographical disruption,^{47,63,81,92} maintaining a sense of 'normality'⁸⁶ and exercising personal control.^{66,70,75,79} Such meaning frameworks helped individuals to cope with sometimes challenging and uncertain self-management practices in the context of their everyday lives, as a woman with encephalitis in one study said,

I know the answers but it's putting them into practice, I still have to. I'll get there eventually. The only advice I can say is try to be as positive, try to get your interests and think outside of it and not dwell on, 'oh, this happened to me and why?' and so on and so forth. Consider it as part of the past. Just try to get on with life.⁶⁴ (p. 390)

In several other studies, self-management was further understood as a demanding process which required hard work: physical, emotional, psychological or biographical.^{88,90,93,95} Those with multiple conditions considered self-management to entail a dynamic process of prioritising one chronic condition over another⁹¹ involving unpredictability⁸⁰ and significant challenges to integrating self-management practices in everyday lives.⁹⁶ Self-management of multiple conditions for some also had moral implications.^{68,94} Participants in one study interpreted self-management as a moral responsibility to maintain one's health, with self-management practices involving self-discipline and personal effort in response to the limitations of professional

intervention.⁹⁴ For example, one woman living with a number of chronic conditions, including arthritis, chronic pain and heart disease said,

You've only got yourself and you have to self-discipline yourself [...] You're your own policeman.⁹⁴ (p. 222)

Self-management as a social practice. Lay understandings of self-management commonly entailed social practices and strategies which required social support from family and friends,^{59–61,63,69,74,77,78,82,84,86,90,92,95,97,98} a theme that was much less often reported among HCPs.^{51,53} In line with social support theory,^{28,29} we found that perceived support from family and friends comprised both positive^{59,61,62,64,69,74,77,78,82,84,86,90,92,95} and negative^{64,78,97,98} influences, which in turn had an impact on self-management practices. Positive influences from family and friends involved the provision of support in activities of daily living and personal care,^{77,84,96} practical support in medication regimes⁷⁸ and transport for GP visits,^{77,78} offering health-related advice and information^{69,74,77,78,86} and financial support.⁸⁴

Other social strategies included peer support and information exchange with other patients⁸⁶ or among those with similar conditions attending social and community groups.⁹⁰ People living with conditions such as arthritis, heart disease and diabetes identified family members and friends as an important source of emotional support for self-management practices.^{78,84,96} Thus, family and friends provided ongoing encouragement, motivation and reassurance,⁹⁶ and opportunities to reinforce self-identity,⁶⁴ share concerns about long-term physical symptoms and management.^{75,78} For example, participants with multiple LTCs in two studies commented,

After she and I talk on the phone, we both feel better when we get finished talking. We talked about taking our medication, we talk about the pains that we have but we can't do nothing about it so we deal with it.⁷⁸ (p. 394)

I try to get someone to confirm that I have done the right thing somehow, to hear that from someone else, as well.⁹⁶ (p. 341)

In several other studies, lay people interpreted self-management as the ability to mobilise emotional and practical support, information and advice from family and friends as part of a proactive approach to their self-management practices.^{57,69,74,82,84,90,92,95,96} Mobilising social support was identified as part of a process of long-term adjustment among people with conditions such as stroke,⁶¹ encephalitis⁶⁴ and MS.⁷⁴

Individuals with chronic conditions also reported negative social support influences from family members on self-management behaviours. This included overprotective family members who discouraged self-management practices,^{78,96} those providing unhelpful advice^{78,96} or who were undermining and lacked understanding and empathy.^{64,78} A

proportion of participants in three studies reported that lack of family support shaped a greater dependence on HCP support in learning self-management skills.^{82,83,92} The availability of social support from family members to assist in self-management practices, however, was at times perceived as a taken-for-granted assumption among HCPs⁷⁷, as one socially isolated male participant with diabetes and no family ties said,

I think the way the medical people see it ... is that you are attached to someone, and that there's somebody there to watch over you ... No, no, there's no family, so it's not that they wouldn't, it's just that there's no-one there ...⁷⁷ (p. 596)

Finally, a minority of studies highlighted how ongoing support in self-management activities had long-term negative effects on carers themselves. This included a negative impact on personal well-being, related to juggling a number of different roles,⁹⁸ family conflicts due to blurring of boundaries with normative kinship practices⁹⁷ and difficulties establishing the perceived correct level of support in self-management practices.⁹⁸

Discussion

Summary of main findings

The aim of this article was to compare lay and HCP understandings of self-management of LTCs, through a systematic review and narrative synthesis of qualitative studies. We found some similarities, but mainly differences in the ways in which these two stakeholder groups interpreted self-management. HCPs and lay people understood self-management in terms of traditional or paternalistic professional–patient relationships premised on compliance with professional advice, but also shifting models of this relationship based on different expectations of responsibility.

Lay people interpreted self-management in terms of the quality of relationship with health professionals. Variations in how individuals put self-management into everyday practice were shaped by differences in preferences for engagement in self-management practices, and how individuals constructed different meaning frameworks and drew on social strategies to cope with, and manage, the challenges of living with chronic conditions. These aspects of self-management were largely not reported by professionals.

Robustness, strengths and limitations of the synthesis

Overall, the quality of studies included met most of the methodological criteria proposed by Dixon-Woods et al.⁴¹ However, one limitation of this brief quality assessment tool is that it did not encourage a critique of the research question posed in the original studies. The quality checklist also focuses on an appraisal of the technical quality of the research

design of a study, and it did not allow for a consideration of theoretical approaches used. We found that over half of studies used one or more theoretical approaches, mostly sociological. This arguably enhanced quality, in that such studies went beyond taking self-management as a given and attempted to understand and contextualise self-management as a social construct. However, just under one-half of studies were largely atheoretical in their scope, reporting only emerging themes. Another aspect likely to have had an impact on the quality of included studies is that the terms self-management and self-care were often used synonymously, despite attempts in the literature to delineate similarities and differences between the two concepts.^{2,3}

A further potential limitation is the inclusion of studies with different methodologies (interviews, focus groups or mixed methods), which could have implications for synthesising findings from these studies. The robustness of the synthesis might also have been affected by only one author (E.S.) conducting the search strategy selection and synthesis of studies. However, the validity of the synthesis was strengthened by using two authors during quality appraisal and data analysis. We recognise that people with LTCs represent a diverse group. Although we focused on the perspectives of individuals with different chronic conditions, including those with multi-morbidity, and the views of a range of HCPs, the synthesis led to a number of recurrent themes.

How our findings relate to the existing literature

Our findings show that, in different ways, lay and HCP understandings of self-management practice deviated from the dominant model of self-management underpinned by the concept of self-efficacy, as promoted in the policy^{10,11} and health care^{15–17} fields. HCP understandings of self-management based on a model of compliance is contrary to an ethos of self-management premised on empowering lay people with LTCs to make their own decisions in terms of managing their health in partnership with HCPs.^{16,18} However, lay people reported variations in expectations of the patient–professional relationship and interpreted self-management in different ways.

In line with studies that have shown how professional attitudes serve to construct tacit notions of what makes a ‘good patient’,^{99,100} our synthesis suggests that HCPs seemed to hold normative values concerning what makes a ‘good self-manager’,^{7,36} based on ideal values related to compliance, motivation and personal responsibility. As Lawn et al.⁷ and Kendall and Rogers¹⁸ have argued, the lack of such characteristics implicitly constructs individuals with LTCs as deficient, such that teaching self-management arguably becomes a moral intervention.

Despite self-efficacy being a dominant trope in the theory of a widespread model of self-management,¹⁵ we found that lay people only partly understood self-management in terms

of self-efficacy enhancing strategies. In an Australian study, Kendall et al.¹⁰¹ similarly found a lack of support for the impact of self-efficacy on engagement in self-management behaviours following long-term adjustment after stroke. As proposed by self-regulation models of self-management,^{21–23} we also found some evidence that lay beliefs about health and illness shaped preferences for engagement in self-management practices. However, our findings support that people with chronic conditions understood self-management to include a number of domains not typically addressed by existing CDSMPs, including differences in expectations of responsibility and the importance of developing collaborative partnerships with health professionals. Lay people further understood self-management as encompassing different meaning frameworks and embedded in social practices. In line with the large body of sociological literature documenting the experiences of individuals living with chronic illness, self-management appeared to be part of the lay construction of illness narratives, enabling people to make sense of, cope with, and adapt to chronic conditions in their everyday lives.²⁴ Self-management further reflected an appraisal of the quality of social support provided from one’s immediate social group, which supports other qualitative studies that have found the quality of social support from informal networks is important in the process of coping and longer term adaptation to chronic illness.^{102–104}

Conclusion and implications for policy and future research

Self-management programmes are increasingly promoted as a panacea for under-resourced health care systems, although evidence of effectiveness of such programmes is lacking. This review found some similarities, but important differences between lay and HCP understandings of self-management of LTCs. This may help to account for the apparently limited effectiveness of self-management interventions, suggesting a mismatch between what is intended and practised.

The review raises a number of implications for policy and future research. First, self-management approaches should not be interpreted only as a way of improving compliance to professional advice and regimes, as this is likely to reinforce traditional practices based on paternalistic health professional–patient relationships, rather than empowering lay people to cope with, and manage the challenges of living with one or multiple chronic conditions. Second, our findings support calls made by others^{18,24–26,34} for the need to develop and evaluate approaches based on social models of self-management, rather than only psychological approaches which largely underpin existing state CDSMPs in health care^{15,17,18}. This means greater attention needs to be paid to the different ways in which lay people understand and interpret self-management and the social context shaping self-management practices.

Third, individual or group self-management interventions need to address differences in lay expectations and abilities to take responsibility in terms of learning self-management skills and to tailor professional support to this end. Fourth, although collaborative professional–patient relationships are considered a mainstay of person-centred care,¹⁰⁵ this was less often recognised among HCPs as an important component of self-management. Given that a significant proportion of people with chronic conditions regarded collaborative partnerships with HCPs as an integral part of their self-management practices, interventions which target improving the quality of professional–patient relationships to foster self-management are warranted.

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The authors declare that there is no conflict of interest.

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